



The Canadian Addison Society La Société canadienne d'Addison

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August 2016

Summer Edition

ISSUE NO. 83

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Distribute to:

PLEASE NOTE:

The content of this newsletter is intended for basic information only and not as personal medical advice. Readers are advised to consult their own doctors before making changes to their Addison/Adrenal Insufficiency management program. Please note that the Society does not endorse the information provided by guest speakers.

News and Announcements

Solu-Cortef Recall – Important Notice

In case you missed our email to all members and our website notice, following is the information provided which will allow you to access the Health Canada Recall Notice on Solu-Cortef.

Attention: Members, Regional Representatives and Directors

We have become aware of a Pfizer recall of Solu-Cortef as announced by Health Canada.

Please refer to the link below which will first take you to the ISMP website:

<https://www.ismp-canada.org/index.htm>

(If the link does not connect you may have to copy and paste the link into your browser window.)

Once at the ISMP site, scroll down to the following link:

August 2nd, 2016 - ISMP Canada News: Health Canada: Solu-Cortef 100 mg/2 mL Act-O-Vial – Recalled Lots due to Potential for Dosing Error

A French version of the Health Canada Recall is available-see top right of their webpage.

The following chart was taken directly from the Health Canada Recall. Please note the dose difference from 2ml with the 100 mg Solu-Cortef Act-O-Vial as you have known it vs .8ml with either of the alternative vials (250mg or 500mg) you may be provided. You may wish to contact your Doctor and/or pharmacist for further clarity.

From Health Canada recall:

If the 250 mg and 500 mg Solu-Cortef vials are used, please follow the instructions to adjust the injection volume as per the table below:

Instructions		
Required dose	Solu-Cortef 100 mg Act-O-vials (single use) (50 mg per mL) Volume of injection	Solu-Cortef 250 mg or 500 mg Act-O-vials (single use) (125 mg per mL) Volume of injection
100 mg	2 mL	0.8 mL

Healthcare professionals should inform and instruct patients on how to appropriately use the correct volume of the alternate vial strength of Solu-Cortef or of the alternative therapeutic product.

News and Announcements *continued*

► We are pleased to introduce our new Newsletter Editor, Shannon Meister. Shannon is an active member of the South Central Ontario Support Group. She is a regular and rarely misses a meeting. Shannon is very active on Facebook interacting with members of the various Addison's/Adrenal Insufficiency Facebook Groups. She will play a leading role when we begin to approach a Social Media initiative. However, first on her agenda will be to get a handle on preparing the Newsletter four times per year. It is a big job and a very important part of our outreach program. Please join me in welcoming Shannon to her new volunteer roles and wishing her success.



Editor's Comments

newsletter@addisonsociety.ca

Hello my fellow Addisonian's, my name is Shannon and welcome to my first issue! I have taken over the Newsletter starting with this my first issue so please bear with me ☺. Please feel free to contact me at the email address shown above and to submit any questions or stories for a future issue.

Personal Experiences

Have you had an experience with Adrenal Insufficiency either as the patient, caregiver, family, friend, nurse, doctor or any other role? Please consider sharing your story for our **Personal Experiences** section, for the benefit of others. You may do so anonymously. Please send to me at the email address shown above. Thanks, Shannon



President's Comments

president@addisonsociety.ca

► Attached is reprint of a letter that I found on Facebook. Although Dr. Rob wrote the article in 2010, it was posted on one of the several Addison Disease Facebook group sites, just last month. A letter from a doctor to those with chronic diseases. Although not specifically directed to Addison's/Adrenal Insufficiency patients, Dr. Rob agrees with us that it's a fit and we are reprinting with his permission. Please take the time to read it: it's so valuable to those on both sides of the desk or hospital bed!

► A Mom in Southern Ontario is seeking to communicate with a family with a young child with AI. She would like to compare notes regarding her 8-year-old daughter who has AI. Her daughter recently had her adrenals removed as a fix for Cushing's. Please contact me at president@addisonsociety.ca and I will connect the two families.

Support Group Contact Information & Meeting Reports

B.C. - Vancouver Island Support Group

Meeting Minutes – 14 May 2016 1:00 to 3:20 PM – Vancouver Island/Victoria Support Group

Five members of the Vancouver Island Support Group met on May 14th in Deep Bay just outside of Victoria. We began the meeting with a very important discussion of the requirement for extra cortisol in periods of stress, infection and illness. Members were reminded to watch for the warning signs of low cortisol; light headed, fainting, weakness, abdominal pain and nausea. Take extra cortisol as directed by your endocrinologist to avoid an adrenal crisis.

Everyone should have a list of their medications and Addison's treatment instructions with them at all times. You or someone with you, may need to present these to an ambulance attendant or at a hospital emergency department.

There was some discussion of the recent price increases by the Medic Alert Foundation. We understand that the foundation is a non-profit organization but we remain concerned with stories of incorrect medical information being engraved and the reluctance of the foundation to make corrections and changes. One member of the support group was able to source a similar medical alert from a company based in Winnipeg.

Some of the members have joined the Addison's Disease Facebook group (#yes I have Addison's). It is another form of support for people with Addison's and for that we are very grateful. However, from time to time we see people seeking medical advice on that page and that we find worrisome.

continued

Support Group Contact Information & Meeting & Report *continued*

B.C. - Vancouver Island Support Group *continued*

We also had a quick discussion of natural treatment of Addison's. This is similar to the medical treatments that were used prior to treat Addison's prior to the introduction of glucocorticoids in the early 1950s. The natural treatment apparently involves using desiccated pork glands. We are not aware of any doctor that is in favour of the natural approach!

Our fall meeting is planned for Saturday October 22, 2016 at 1:00PM

One more thing.... We are quite worried about the small number of people attending our meetings lately. If you have any suggestions or ideas on how to improve our meetings, we would love to hear from you. We welcome any and all feedback you may have!! Derek

Addison's Abstracts May 14, 2016

1) Incidence of adrenal crisis in patients with adrenal insufficiency

Authors - Lisanne Smans, Pierre Zelissen, Utrecht, Netherlands

<http://onlinelibrary.wiley.com/doi/10.1111/cen.12865/full>

2) Mild cognitive deficits in patients with primary adrenal insufficiency

Authors - Jitske Tiemensma, Alberto Pereira Leiden, Netherlands

[http://www.psyneuen-journal.com/article/S0306-4530\(15\)00932-4/abstract](http://www.psyneuen-journal.com/article/S0306-4530(15)00932-4/abstract)

3) Adrenocortical endocrine disruption **Author** - Philip W. Harvey, Toxicology Dept. Covance Laboratories, North Yorkshire, UK

<http://www.sciencedirect.com/science/article/pii/S0960076014002441?np=y>

4) Salivary Cortisone Reflects Cortisol Exposure Under Physiological Conditions After Hydrocortisone

Authors - Miquel Debono, Wiebke Arlt, Richard Ross, Sheffield, UK

<http://press.endocrine.org/doi/abs/10.1210/jc.2015-3694>

5) Effect of steroid replacement on thyroid function and thyroid autoimmunity in Addison's disease with primary hypothyroidism

Authors - Jaya Prakash Sahoo, Puducherry, India

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4792014/>

6) Decreased physical activity, reduced QoL and presence of debilitating fatigue in patients with Addison's disease

Authors - Eline S. van der Valk, Pierre Zelissen, Netherlands

<http://onlinelibrary.wiley.com/doi/10.1111/cen.13059/abstract>

7) Polymorphisms of the GR and HSD11B1 genes influence body mass index and weight gain during hormone replacement treatment in patients with Addison's disease **Author** - Agnes Molnar, Budapest, Hungary

<http://onlinelibrary.wiley.com/doi/10.1111/cen.13022/full>

8) Effect of a pre-exercise hydrocortisone dose on short term physical performance in 2 female patients with primary adrenal failure

Authors - Katerina Simunkova, Kristian Løvås, and Eystein S. Husebye, Bergen, Norway

https://www.researchgate.net/profile/Espen_Rostrup/publication/283208284_Effect_of_a_pre-exercise_hydrocortisone_dose_on_short_term_physical_performance_in_female_patients_with_primary_adrenal_failure/links/5633384308ae911fcd4a67a4.pdf

continued

Support Group Contact Information & Meeting Reports *continued*

B.C. - Vancouver Island Support Group *continued*

9) **Reduction in daily hydrocortisone dose improves bone health in primary adrenal insufficiency** Authors - Julia Schulz, Marcus Quinkler, Berlin, Germany

<http://www.eje-online.org/content/174/4/531.short>

10) **Addison's disease with polyglandular autoimmunity carries a more than 2.5-fold risk for adrenal crises: German Health insurance data 2010–2013**

Author - Gesine Meyer, Germany

<http://onlinelibrary.wiley.com/doi/10.1111/cen.13043/abstract>

For further information on the Vancouver Island Support Group, please contact Derek Clarke at vancouverislandaddisons@gmail.com or (250) 857-4320.

For information on Central Island activities, please contact Sharon Erickson at ericksons@shaw.ca. "

BC - Lower Mainland Support Group

For further information on this Support Group please contact Judy Stanley at, bugbee@shaw.ca

Alberta - Edmonton Region Support Group

For information on this support group, contact Ginny Snaychuk at ginray@shaw.ca or (780) 454-3866 in Edmonton

We are searching for a volunteer to take on the Regional Representative role in the **Edmonton** Region. If you are interested, please contact either Ginny Snaychuk at ginray@shaw.ca or Harold Smith at president@addisonsociety.ca.

Alberta - Calgary Region Support Group

For information on this support group, contact Ginny Snaychuk at ginray@shaw.ca or (780) 454-3866 in Edmonton

We are searching for a volunteer to take on the Regional Representative role in the **Calgary** Region. If you are interested, please contact either Ginny Snaychuk at ginray@shaw.ca or Harold Smith at president@addisonsociety.ca

Saskatchewan Support Group

For information on the Saskatchewan Support Group, contact Elizabeth Hill at (306) 236-5483 elizabethhill10@hotmail.com

The next meeting is expected be held in the Regina area – date and location have not yet been determined. ...

Continued.

Support Group Contact Information & Meeting Reports *continued*

Ontario - South/Central Support Group

The South Central Ontario Support Group met in Mississauga on Saturday, May 14 at The Erin Mills United Church. There was a fabulous turnout of about 40 people including a number of first timers whom we were all glad to welcome. The couple from the furthest point in the region, were Anna and Ken Toal from North Bay which represents a one-way trip of about 350 kilometers and 3 ½ hours. Others attending previous meetings have travelled similar distances.

We also had an International visitor from Jamaica, Julie who is an Addisonian and had been communicating with us by email and Skype. Good fortune had her in Canada visiting with her brother and his wife at the time of our meeting.

Member Shannon Meister, currently this group's photographer has agreed to take over as the Society's national Newsletter Editor and Social Media coordinator for The Canadian Addison Society, effective immediately. Our Thanks to Shannon for taking up this most important role for the Society. Our thanks also go to Carrie Smith for her time as Newsletter Editor.

Our Special Guest Speaker was Dr. Donald Killinger, Endocrinologist practicing in Etobicoke, Ontario. Dr. Killinger is of course the Society's Medical Advisor. While it has been some time since his last presentation at an AGM or Support Group Meeting, Dr. Killinger is busy providing medical guidance to the Society on a regular basis. He is also busy with our *Question & Answer* service on the website.

In addition, we often call on Dr. K for review of such information documents as the new member card and new brochure published last year, to be sure all information is medically correct. Dr. K's service to the Society has been huge over many years and we are very grateful for his volunteer contribution.

The new brochure mentioned above may be found [http://www.addisonsociety.ca/files/pdfs/CASBROCHURE\(1\).pdf](http://www.addisonsociety.ca/files/pdfs/CASBROCHURE(1).pdf)

Following are comments & questions that arose during the meeting and are transcribed by non-medical volunteers and do not represent medical advice. Please refer to Dr. Killinger's Power Point Presentation included in this Newsletter for further clarity.

It was noted that with a prevalence of Addison's disease estimated about 10 per 100,000, most Endocrinologists may have only 4 patients. This is anticipated to be the same in USA as in Canada.

•Sources for primary or secondary adrenal insufficiency

(Addison's disease, panhypopituitarism, auto-immune polyglandular syndrome, secondary to inhaled corticosteroids (asthma), etc.).

Discussion of primary reasons for adrenal crises: (stroke, thyroid medication, infections, surgery, rapid steroid reduction, accidents, etc.)

Delayed treatment with hydrocortisone for an adrenal crisis continues to be a concern in the pre-hospital and hospital settings.

Miscellaneous comments during the meeting as follows:

How to determine dosing- some agree they are over replaced.

A. you need the smallest amount that will make you feel okay- potential to decrease secondary problems such as Diabetes and Osteoporosis. Members also discussed challenges with respect to dose reduction for glucocorticoid regimen.

Some members described the need to change glucocorticoids based on absorption issues and/or celiac disease.

Others discussed complications with co-existing conditions (diabetes, thyroid, etc.).

Difference between Cortef, Prednisone was discussed.

HC (Cortef)- peaks in about 2 hours and lasts about 4-6 hours Prednisone- peaks in about 4 hours and lasts about 6-8 hours Dexamethasone- 12hrs no peak not used often since often.

continued

Support Group Contact Information & Meeting Reports *continued*

Ontario - South/Central Support Group *continued*

As Cortef peaks in 2 hours, if you took it at 6 am and got up at 8 am you would be at its peak time. This is not the same for Prednisone which peaks in about 4 hours. Prednisone is harder on the bones and some risk for Cushing's symptoms

DHEA - you will not have it if you have Addison's -many studies prove it doesn't really help

In USA, DHEA is a health food supplement but not well regulated. 25mg would be a normal production rate for the body and at 25 mg there are not many side effects. However, 50 mg may have side effects for some.

The Fall meeting of this support group is scheduled for October 1, 2016 at the College Avenue Church, 22 Wilson St, Woodstock. Registration opens at 12.30 pm and the meeting begins at 1.00 pm with adjournment at 4.30 pm This Support Group meeting will also host the Society's **2016 Annual General Meeting**. We are pleased to advise that our **Guest Speaker** will be **Stan Van Uum, MD, PhD, FRCPC** Program Director Endocrinology and Metabolisms Associate Professor Endocrinology & Metabolism Clinical Pharmacology Dept. of Medicine, Western University.

An **Emergency Injection Training Clinic** will be part of the October 1 program.

<http://www.addisonsociety.ca/index.php/community/support-group-meetings>

For further information on South/Central Ontario Support Group activities or meetings, please contact Harold Smith in Kitchener-Waterloo at hsmith81@hotmail.ca or (519) 742-8170.

Ontario - Eastern Support Group

The Eastern Ontario Support Group met on Saturday, May 14, 2016, at Robbie's Restaurant in Ottawa. There were fifteen in attendance. Our guest speaker in attendance was Marylène Caron B.Sc. R.Ph., a local registered pharmacist from Jean Coutu, Embrun, Ontario.

She discussed mainly corticosteroid replacement therapy in Addison's disease. It can be concluded that each medical treatment must be individualized and therefore a drug regimen may vary greatly from different Addison's patients. Sick day protocols may also vary widely as well. She distributed a few examples of sick day protocols. She outlined briefly the most commonly used medications and their respective dosage.

Mineralocorticoid replacement with Florinef 0.1mg tabs (fludrocortisone) was discussed. Paladin, the manufacturer of Florinef confirmed that the product is stable at room temperature (15 to 25 degrees Celsius) only for 30 days and should be stored in the refrigerator (at 2 to 8 degrees Celsius).

Glucocorticoids include: Cortef tablets (hydrocortisone), Cortone tablets (cortisone acetate), Decadron tablets (dexamethasone), Solu-Cortef Act-O-vial injections (hydrocortisone sodium succinate) etc. She discussed a few important side effects associated with chronic use of such medications such as

Ontario - Eastern Support Group *continued*

osteoporosis, immunosuppressive effects, gastrointestinal irritation, reflux, cataracts, etc. Since numerous complications can arise, she recommended regular visits to their health professionals (family physician or specialist, dentist and optometrist etc.). She offered a few helpful medication reminder tips and services the pharmacy can offer their patients to enhance compliance. Pharmacies can provide services such as cutting tablets, making calendars to assist in drug dosage tapering, and flagging regularly taken medications to prepare them ahead of time. Pharmacists can conduct a 'MedsCheck' (a comprehensive medication review which includes creating an up to date medication list. The pharmacist is permitted to refill certain medications which are taken regularly without having to contact the prescriber beforehand. They can also transfer refills of certain medications across Canada in accordance with the law. She also answered questions from the group about Januvia (sitagliptin) a new hypoglycemic agent. She strongly feels that vitamin supplements should be discussed with doctors.

continued

Support Group Contact Information & Meeting Reports *continued*

Ontario - Eastern Support Group *continued*

Every Addison's patient should wear a Medic Alert bracelet and have a letter from their endocrinologist describing their condition and emergency treatment. A copy of Dr. Silverman's hospital protocol for Addison's crisis was circulated

for people to see. Addison's patients should have a supply of extra medications on hand in case of travel or emergency, including Solu-Cortef vials. It was suggested that the higher strength of Solu-Cortef should be available in case of an emergency, e.g.: 250mg vial instead of 100mg vial because in a moment of panic, in an emergency, there could be wastage.

When the floor was open for discussion, expired medications were discussed. As a rule, the pharmacist **always** goes by the book and will never recommend using expired pharmaceutical products but in an emergency, good judgement shall prevail.

Products that are on long-term back order or discontinued should not be a source of worry to you. It should be strongly emphasized that supply and other issues with pharmaceuticals in other countries do not necessarily mean there are similar problems in Canada.

Most computer software will detect drug interactions and pharmacists do check more than one source of information to verify all possible drug interactions. The Grapefruit (Citrus paradisi) and corticosteroids drugs interaction is well documented: the combination may increase corticosteroid levels and the risk of adverse effects (GI metabolism inhibited). As corticosteroid requirements in Addison's can also increase, one should not be overly worried but vigilant.

The last item presented at the meeting was the presentation with the "vial of life", a pilot project sponsored by the *Fédération des aînés et des retraités francophones de l'Ontario* to help Paramedics quickly find medical list of patients in emergencies.

The dynamic group animated the discussion with their interesting personal experiences living with Addison's.

For information on Eastern Ontario Support Group activities or meetings, please contact Ghislain Hardy, email ghislain2406@live.ca or telephone (613) 601-3671. *Those located in Quebec, near Ottawa, would be most welcome at our meetings.*

Quebec - Montreal Region Support Group

For information on Montreal Region Support Group activities or meetings, please contact Shelley Saklatvala, email shell326@hotmail.com or telephone (514) 991-0294.

Quebec - Québec City Region Support Group

We are searching for a volunteer to become our Regional Representative for a Quebec City Region Support Group. If you are able to assist in this volunteer role please contact Harold Smith, president@addisonsociety.ca. In the interim, if you are trying to connect with the Society for support please call our Montreal Area Regional Representative, Shelley Saklatvala at (514)-991-0294 or you may **also call the Society via our Toll Free number 1-888-550-5582 or email info@addisonsociety.ca or president@addisonsociety.ca.**

Atlantic Support Group

For information on the Atlantic Canada Support Group activities or meetings, please contact, Holly Mclean email hquilter@nb.sympatico.ca or telephone 506-546-1687. Holly lives in northern New Brunswick

Medical Q & A's

There is a very large and wide-ranging set of questions on both daily living and situation-specific issues that have been answered by our medical advisor over the years. Before submitting a question to our medical advisor, please consult the wealth of Q&A's on our website. Many questions have already been answered.

To review these questions and answers, please go to the Canadian Addison Society website under Education <http://www.addisonsociety.ca/files/pdfs/FAQNovember2011.pdf> see previous issues of the newsletter.

Question 1 :

After a number of years using both inhaled and oral steroids (pred) for frequent asthma flares, I developed many symptoms of secondary adrenal insufficiency. After both am serum cortisol tests (below reference range) and a stim test, my (first) endo declared that I had "partial adrenal insufficiency" but would only need "supplemental steroids" for severe illness or surgery. I sought a second opinion, and was recently told by my endo that my am cortisol level was 23, and that my adrenals had shown "no recovery". But he still wanted me to very slowly try to completely taper. This has been impossible due to 2 recent viruses that led to chest infections and asthma flares. Neither endo suggested either a med alert bracelet or emergency injection kit; my asthma doctor recommended both, but has left it up to endo. Since I'm currently attempting to taper down from 80 mg, am currently at 60 but struggling with low cortisol symptoms (nausea, vomiting, abdominal pain) do you think I need an injection kit? I have purchased a med alert bracelet, but haven't yet had it engraved. Thanks for considering my situation and question!

Response 1 :

Since I do not know the details of your treatment and your history, I can not be specific in answering your questions. If you have been on puffers and prednisone for several years, it is likely that you have some suppression of your pituitary and your adrenals. It depends on how much time you have been on the steroids and how much time off. When you are on prednisone, your morning cortisol is going to be low because your pituitary is suppressed by the prednisone. The amount of prednisone that is equivalent to your normal daily secretion of hydrocortisone is about 7.5 mg. This means that as long as you are on a dose of prednisone greater than 7.5 mg, your pituitary and adrenals will be suppressed and your morning cortisol will probably be suppressed. Prednisone is not measured in the hydrocortisone assay. If you are on 60 mg of prednisone, you will have to slowly taper the dose as your endocrinologist had mentioned. Whether you can do this depends on your asthma. If it flairs up you have to increase your prednisone until you feel better, then again start to slowly taper the hydrocortisone.

How suppressed your pituitary and adrenals are depends on how much prednisone you have been on and for how long. Your own pituitary and adrenals will not be stimulated until your prednisone dose is less than 7.5 to 10 mg per day. At that stage, you have to taper even more slowly.

You must do your tapering with the help of your endocrinologist. Getting off steroids, both oral (prednisone) and puffers, can be difficult and requires patience. There may be times when you do not feel as well as you would like but it is important to stick with the program as long as your asthma does not flare up.

I think the bracelet is important and should say that you are on prednisone, in an emergency requires Solu-Cortef. The emergency kit cannot do you any harm and hopefully you will not need it. If you get it, be sure you or a companion learns how to use it.

Medical Questions and Answers

Dr. Donald Killinger, MD, PhD, FRCPC

Medical Advisor to The Canadian Addison Society

will answer your questions about Addison's/Adrenal Insufficiency.

Send your question to Dr. Killinger directly from the webpage or this link

<http://www.addisonsociety.ca/index.php/education/faqs/ask-a-question>

Or by emailing info@addisonsociety.ca Or via Canada Post to

The Canadian Addison Society, 2 Palace Arch Drive, Etobicoke, Ontario M9A 2S1

Questions and answers that may be of interest to everyone may be published in the Newsletter and on the website.

A LETTER TO PATIENTS WITH CHRONIC DISEASE

July 14, 2010
by Rob Lamberts

Dear Patients: You have it very hard, much harder than most people understand. Having sat for 16 years listening to the stories, seeing the tiredness in your eyes, hearing you try to describe the indescribable, I have come to understand that I too can't understand what your lives are like. How do you answer the question, "how do you feel?" when you've forgotten what "normal" feels like? How do you deal with all of the people who think you are exaggerating your pain, your emotions, your fatigue? How do you decide when to believe them or when to trust your own body? How do you cope with living a life that won't let you forget about your frailty, your limits, your mortality?

I can't imagine.

But I do bring something to the table that you may not know. I do have information that you can't really understand because of your unique perspective, your battered world. There is something that you need to understand that, while it won't undo your pain, make your fatigue go away, or lift your emotions, it will help you. It's information without which you bring yourself more pain than you need suffer; it's a truth that is a key to getting the help you need much easier than you have in the past. It may not seem important, but trust me, it is.

You scare doctors.

No, I am not talking about the fear of disease, pain, or death. I am not talking about doctors being afraid of the limits of their knowledge. I am talking about your understanding of a fact that everyone else seems to miss, a fact that many doctors hide from: we are normal, fallible people who happen to doctor for a job. We are not special. In fact, many of us are very insecure, wanting to feel the affirmation of people who get better, hearing the praise of those we help. We want to cure disease, to save lives, to be the helping hand, the right person in the right place at the right time.

But chronic unsolvable disease stands square in our way. You don't get better, and it makes many of us frustrated, and it makes some of us mad at you. We don't want to face things we can't fix because it shows our limits. We want the miraculous, and you deny us that chance.

And since this is the perspective you have when you see doctors, your view of them is quite different. You see us getting frustrated. You see us when we feel like giving up. When we take care of you, we have to leave behind the illusion of control, of power over disease. We get angry, feel insecure, and want to move on to a patient who we can fix, save, or impress. You are the rock that proves how easily the ship can be sunk. So your view of doctors is quite different.

Then there is the fact that you also possess something that is usually our domain: knowledge. You know more about your disease than many of us do – most of us do. Your MS, rheumatoid arthritis, end-stage kidney disease, Cushing's disease, bipolar disorder, chronic pain disorder, brittle diabetes, or disabling psychiatric disorder – your defining pain – is something most of us don't regularly encounter. It's something most of us try to avoid. So you possess deep understanding of something that many doctors don't possess. Even doctors who specialize in your disorder don't share the kind of knowledge you can only get through living with a disease. It's like a parent's knowledge of their child versus that of a pediatrician. They may have breadth of knowledge, but you have depth of knowledge that no doctor can possess.

So when you approach a doctor – especially one you've never met before – you come with a knowledge of your disease that they don't have, and a knowledge of the doctor's limitations that few other patients have. You see why you scare doctors? It's not your fault that you do, but ignoring this fact will limit the help you can only get from them. I know this because, just like you know your disease better than any doctor, I know what being a doctor feels like more than any patient could ever understand. You encounter doctors intermittently (more than you wish, perhaps); I live as a doctor continuously.

continued

Dr., Rob continued

So let me be so bold as to give you advice on dealing with doctors. There are some things you can do to make things easier, and others that can sabotage any hope of a good relationship:

Don't come on too strong – yes, you have to advocate for yourself, but remember that doctors are used to being in control. All of the other patients come into the room with immediate respect, but your understanding has torn down the doctor-god illusion. That's a good thing in the long-run, but few doctors want to be greeted with that reality from the start. Your goal with any doctor is to build a partnership of trust that goes both ways, and coming on too strong at the start can hurt your chances of ever having that. Show respect – I say this one carefully, because there are certainly some doctors who don't treat patients with respect – especially ones like you with chronic disease. These doctors should be avoided. But most of us are not like that; we really want to help people and try to treat them well. But we have worked very hard to earn our position; it was not bestowed by fiat or family tree. Just as you want to be listened to, so do we.

Keep your eggs in only a few baskets – find a good primary care doctor and a couple of specialists you trust. Don't expect a new doctor to figure things out quickly. It takes me years of repeated visits to really understand many of my chronic disease patients. The best care happens when a doctor understands the patient and the patient understands the doctor. This can only happen over time. Heck, I struggle even seeing the chronically sick patients for other doctors in my practice. There is something very powerful in having understanding built over time.

Use the ER only when absolutely needed – Emergency room physicians will always struggle with you. Just expect that. Their job is to decide if you need to be hospitalized, if you need emergency treatment, or if you can go home. They might not fix your pain, and certainly won't try to fully understand you. That's not their job. They went into their specialty to fix problems quickly and move on, not manage chronic disease. The same goes for any doctor you see for a short time: they will try to get done with you as quickly as possible.

Don't avoid doctors – one of the most frustrating things for me is when a complicated patient comes in after a long absence with a huge list of problems they want me to address. I can't work that way, and I don't think many doctors can. Each visit should address only a few problems at a time, otherwise things get confused and more mistakes are made. It's OK to keep a list of your own problems so things don't get left out – I actually like getting those lists, as long as people don't expect me to handle all of the problems. It helps me to prioritize with them.

Don't put up with the jerks – unless you have no choice (in the ER, for example), you should keep looking until you find the right doctor(s) for you. Some docs are not cut out for chronic disease, while some of us like the long-term relationship. Don't feel you have to put up with docs who don't listen or minimize your problems. At the minimum, you should be able to find a doctor who doesn't totally suck.

Forgive us – Sometimes I forget about important things in my patients' lives. Sometimes I don't know you've had surgery or that your sister comes to see me as well. Sometimes I avoid people because I don't want to admit my limitations. Be patient with me – I usually know when I've messed up, and if you know me well I don't mind being reminded. Well, maybe I mind it a little. You know better than anyone that we docs are just people – with all the stupidity, inconsistency, and fallibility that goes with that – who happen to doctor for a living. I hope this helps, and I really hope you get the help you need. It does suck that you have your problem; I just hope this perhaps decreases that suckishness a little bit.

Sincerely,

Dr. Rob

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<http://doctorlamberts.org/>

Dr. Killinger's
presentation
given at the
May 14, 2016
meeting of the
South Central Ontario
Support Group
follows.

Canadian Addison's Society

May 14, 2016

Management of Adrenal Insufficiency

Frequently asked Questions

FREQUENTLY ASKED QUESTIONS

The responses given during the discussion of these questions are only examples of possible solutions. They are designed to provide general information to understand how to deal with a situation.

The examples may discuss doses of medication but these doses may not be appropriate for a particular person. Any dose change must be discussed with your physician.

FREQUENTLY ASKED QUESTIONS

It is important to have an open interaction with your endocrinologist so you feel free to ask questions. All questions have merit. Sometimes the most simple questions are the most difficult to answer.

Not every question has a simple answer.

Addison's disease is a deficiency of adrenal hormones. There are no naturopathic or homeopathic preparations that are beneficial.

FREQUENTLY ASKED QUESTIONS

1. What is the difference between Cortef ,cortisol (hydrocortisone) and prednisone and why do doctors vary on what they prescribe? Does it matter?
2. Maintenance dosing is relatively stable and somewhat simple to maintain for many and yet very difficult for some to achieve. For those struggling to find the proper balance, are there specific strategies, or an orderly methodology they could employ?

FREQUENTLY ASKED QUESTIONS

3. Stress dosing- how do we know when to do this, how much extra to take, for how long, for what?
4. How will we know the oral stress dose is not working and it is time to give the emergency injection and call 911?

FREQUENTLY ASKED QUESTIONS

5. Exercise and extra dosing requirements. How do we know how much extra? How often?
6. How can we best communicate with an endocrinologist who is giving us what we suspect is incorrect advice?

FREQUENTLY ASKED QUESTIONS

- 1. What is the difference between Cortef (hydrocortisone) and prednisone and why do doctors vary on what they prescribe? Does it matter?**

	Duration of Action	Peak Action
Hydrocortisone (cortisol, Cortef)	4 – 6 hours	2 hours
Cortisone, is converted to cortisol in the liver		
Prednisone	6 - 8 hours	4 hours
Dexamethasone	12 hours	no peak
Fludrocortisone (Florinef)	for salt retention only	

FREQUENTLY ASKED QUESTIONS

1. What is the difference between Cortef (hydrocortisone) and prednisone and why do doctors vary on what they prescribe? Does it matter?

Prednisone is slower to act so is not good for starting in the morning.

Prednisone is long acting and is more likely to cause a decrease in bone density and hip fractures.

There is a greater probability of over treatment with prednisone resulting in abdominal weight gain.

FREQUENTLY ASKED QUESTIONS

1. What is the difference between Cortef (hydrocortisone) and prednisone and why do doctors vary on what they prescribe? Does it matter?

Hydrocortisone (cortisol) acts quickly, peaks at 2 hrs, some activity by 1 hr. Half life (disappearance rate) 90 to 120 min, by 2-3 hrs, the blood level falls to $\frac{1}{2}$ previous level.

Treatment 3 or 4 times daily provides coverage in keeping with, but **not** the same, as the normal diurnal variation.

The timing of the doses can be varied depending on the response of the individual.

FREQUENTLY ASKED QUESTIONS

- 2. Maintenance dosing is relatively stable and somewhat simple to maintain for many and yet very difficult for some to achieve. For those struggling to find the proper balance, are there specific strategies, or an orderly methodology they could employ?**

Studies have shown using quality of life questionnaires that individuals on 3 doses of cortisol daily feel better than those taking 2 doses daily.

Another study has demonstrated that individuals taking 4 doses of cortisol daily had a better score on the quality of life questionnaire than those on 2 doses daily

Many individuals do well on 2 or 3 doses of cortisol daily. For those not doing well on this regimen, there is a trial process to find the best routine.

-increase the frequency of dosing eg, 10, 5, 2.5, 2.5 mg
 10 10 5 2.5
 6AM, 10AM, 2PM, 6PM

-if it does not keep you from sleeping, add 1.25 mg at 9 or 10PM

-try 1 mg of prednisone at bedtime.

FREQUENTLY ASKED QUESTIONS

2. Maintenance dosing is relatively stable and somewhat simple to maintain for many and yet very difficult for some to achieve. For those struggling to find the proper balance, are there specific strategies, or an orderly methodology they could employ?

If I am taking my cortisol as prescribed and do not feel well, how do I know that I am absorbing it ?

This can be tested by asking your doctor to measure your cortisol level in the morning before taking your cortisol then again 2 hours and 4 hours later.

This will show the blood level you achieve after taking your morning dose and the rate that it is metabolized.

This is not done frequently so your doctor may be reluctant to do it, but it may be helpful in a situation where the response to treatment does not seem to be appropriate.

FREQUENTLY ASKED QUESTIONS

2. Maintenance dosing is relatively stable and somewhat simple to maintain for many and yet very difficult for some to achieve. For those struggling to find the proper balance, are there specific strategies, or another methodology they could employ?

There are two long acting forms of cortisol that have been studied for a few years in Europe and the UK but have not been released in Canada.

Chronocort – has an enteric coating . It is given at bedtime (20 mg) to achieve the morning cortisol level and in the morning (10 mg) to provide the afternoon level.

Plenandren – a long acting preparation given once daily in the morning but it does not provide the morning rise in cortisol.

FREQUENTLY ASKED QUESTIONS

2. Maintenance dosing is relatively stable and somewhat simple to maintain for many and yet very difficult for some to achieve. For those struggling to find the proper balance, are there specific strategies, or another methodology they could employ?

-Continuous subcutaneous glucose infusion.

- uses solucortef, 50 mg/ml in a constant infusion pump used for insulin infusion.

- the daily dose of cortisol is similar to the usual oral daily dose.

- bolus injections are given in the morning and at lunch along with the constant infusion

- additional bolus injections are given in response to stress.

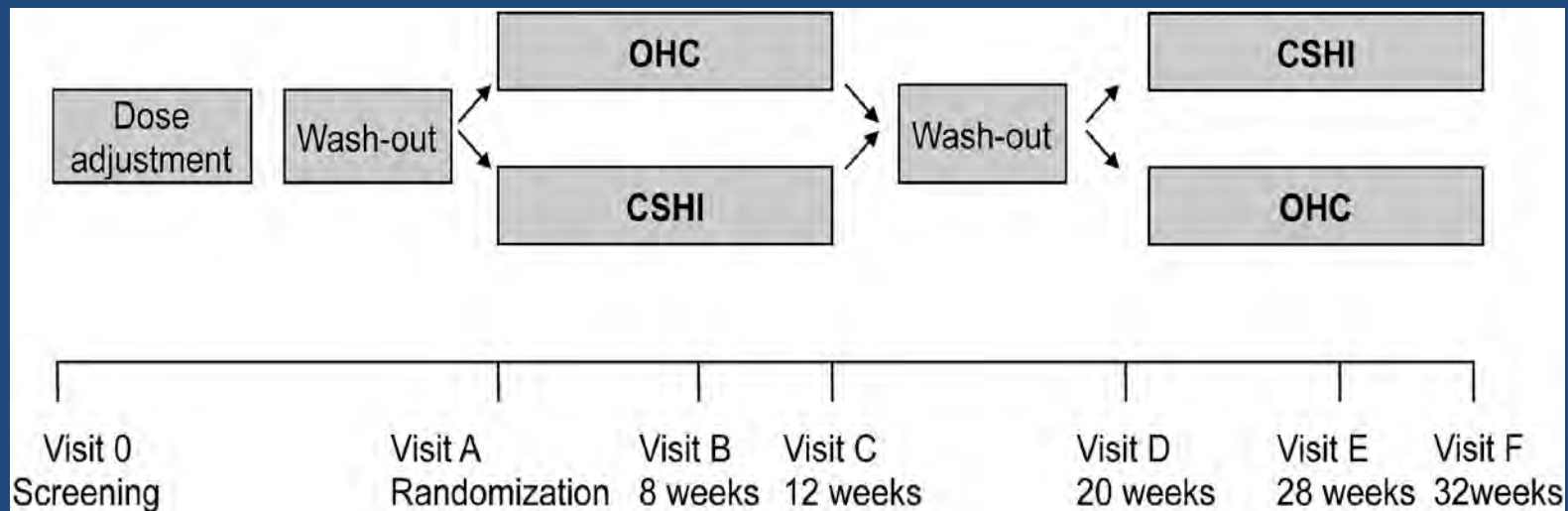
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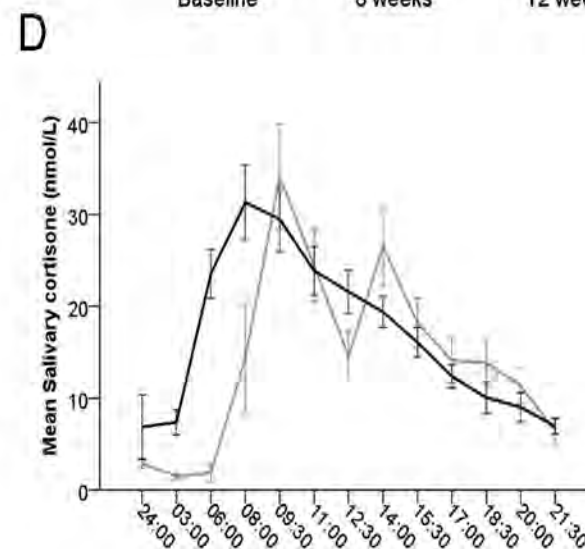
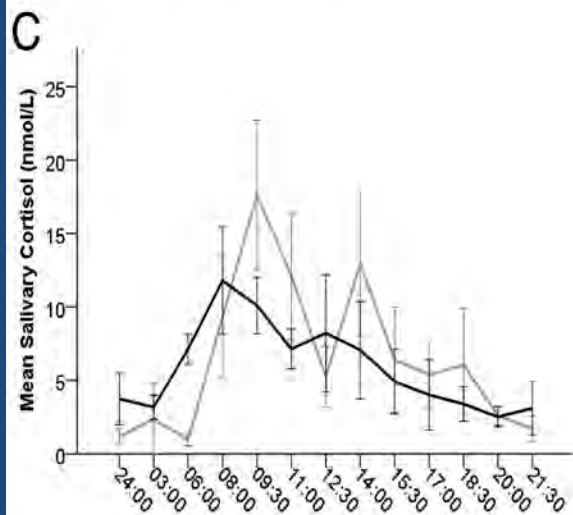
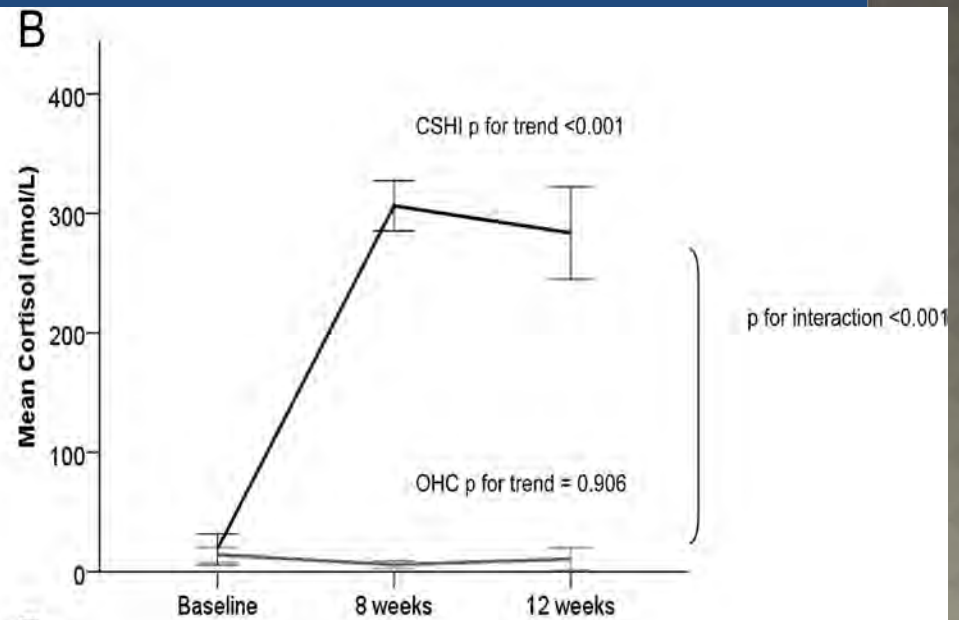
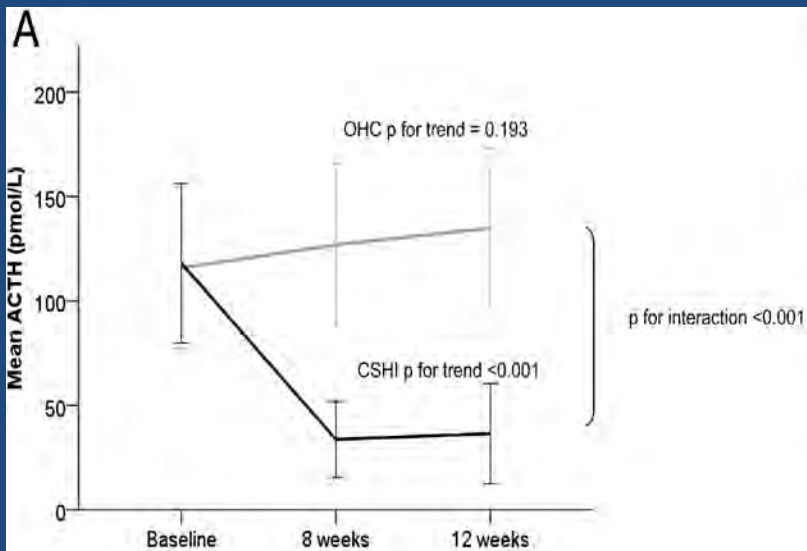
- pump is programmed to provide blood levels in keeping with a normal diurnal variation.

WHAT IS THE CURRENT STATE OF CONTINUOUS INFUSION PUMPS TO ADMINISTER HYDROCORTISONE?

Continuous Subcutaneous Hydrocortisone Infusion versus Oral Hydrocortisone Replacement for Treatment of Addison's Disease: A Randomized Clinical Trial

33 patients





WHAT IS THE CURRENT STATE OF CONTINUOUS INFUSION PUMPS TO ADMINISTER HYDROCORTISONE?

Continuous Subcutaneous Hydrocortisone Infusion versus Oral Hydrocortisone Replacement for Treatment of Addison's Disease: A Randomized Clinical Trial

Subjects completed a health related quality of life study at the end of the study period to determine their response to either treatment

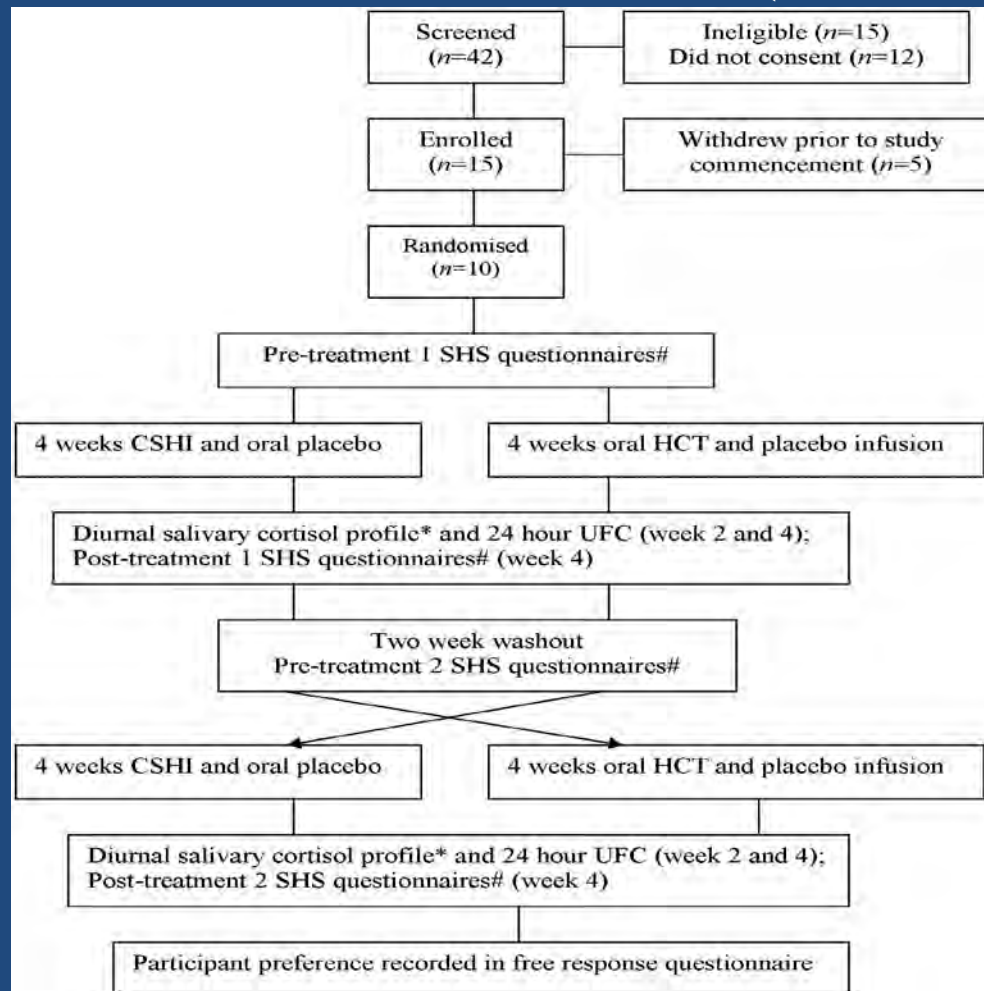
Conclusion:

CSHI safely brought ACTH and cortisol toward normal circadian levels without adversely affecting glucocorticoid metabolism in the way that OHC did.

Positive effects on HRQoL were noted with CSHI, indicating that physiological glucocorticoid replacement therapy may be beneficial and that CSHI might become a treatment option for patients poorly controlled on conventional therapy. (*J Clin Endocrinol Metab* 99: 1665–1674, 2014)

WHAT IS THE CURRENT STATE OF CONTINUOUS INFUSION PUMPS TO ADMINISTER HYDROCORTISONE?

Continuous Subcutaneous Hydrocortisone Infusion Therapy in Addison's Disease: A Randomized, Placebo-Controlled Clinical Trial (10 Patients)



WHAT IS THE CURRENT STATE OF CONTINUOUS INFUSION PUMPS TO ADMINISTER HYDROCORTISONE?

Continuous Subcutaneous Hydrocortisone Infusion Therapy in Addison's Disease: A Randomized, Placebo-Controlled Clinical Trial

Conclusions:

Biochemical measurements indicate similar cortisol exposure during each treatment period, although a more circadian pattern was evident during CSHI.

CSHI does not improve subjective health status (SHS) in AD with good baseline SHS.

This casts some doubt on the potential benefit of circadian cortisol delivery on SHS in AD. (*J Clin Endocrinol Metab* 99: 4149–4157, 2014)

FREQUENTLY ASKED QUESTIONS

3. Stress dosing-how do we know when to do this, how much extra to take, for how long, for what?

There is no specific answer to this question because , to some degree, it depends on the person.

“You have to think for your adrenals”.

The daily secretion of cortisol is 15 - 25 mg. In response to major surgery it is estimated 75—100 mg of extra cortisol is secreted.

For surgery

It is customary for the anaesthetist to give 100 mg of solucortef IV prior to anaesthesia.

Another 100 mg may be required during the next 24 hr

FREQUENTLY ASKED QUESTIONS

3. Stress dosing-how do we know when to do this, how much extra to take, for how long, for what?

For a minor procedure, such as dental work, an extra 10 or 20 mg of cortisol should be sufficient. This depends on how long or how difficult is the procedure.

For febrile illnesses, double or triple the daily dose is recommended until recovery, generally 2 to 3 days.

If there is vomiting and oral intake is not possible, injection of solucortef 100 mg, early is recommended. This is given intramuscularly (IM).

FREQUENTLY ASKED QUESTIONS

3. Stress dosing-how do we know when to do this, how much extra to take, for how long, for what?

There is both physical and emotional stress. Emotional stress has not been studied, but generates a physical stress that requires a response.

Normally, stress results in the release of cortisol and adrenalin. Additional cortisol may be required for short periods during acute emotional stress eg. Double daily dose, but this should not be carried on for prolonged periods or it can create the negative consequences of excess cortisol.

FREQUENTLY ASKED QUESTIONS

4. How will we know the oral stress dose is not working and it is time to give the emergency injection and call 911?

The answer to this has to be subjective.

- If you are vomiting, take the emergency injection and/or go to the emergency dept.
- If you are feeling very unwell and have doubled or tripled your daily dose and are still feeling unwell, go to the emergency dept.
- go before you have to call 911.
- you need fluid replacement as well as cortisol.

FREQUENTLY ASKED QUESTIONS

5. Exercise and extra dosing requirements. How do we know how much extra? How often?

You have to work this out by trial and error. (hopefully without too many errors).

If you go to the gym and you do not normally go to the gym it will be slightly stressful so you could take an extra $\frac{1}{2}$ or 1 tablet before going.

If you go jogging you may need more but it depends on whether you do this regularly. If you are in good condition, the stress will be less. Try an extra tablet and see how it feels.

If you are doing a marathon, you may need to take another tablet every hour.

FREQUENTLY ASKED QUESTIONS

6. How can we best communicate with an endocrinologist who is giving us what we suspect is incorrect advice?

- Why do you feel this way?
 - is it because you are not feeling well?
 - is it because you would like to try other medication?
 - you have heard about other treatment regimens that you would like to try but cannot get cooperation?
 - is it because she/he does not answer you questions and discuss your concerns?

FREQUENTLY ASKED QUESTIONS

6. How can we best communicate with an endocrinologist who is giving us what we suspect is incorrect advice?

- tell the endocrinologist that you would like to have some time to review your situation.
- write down what you want to discuss so you will not get distracted during the meeting.
- ask for explanations of things you do not understand or that do not make sense to you.
- ask if there are references that you can read to help clarify the situation you are concerned about.
- be careful about what you read on the internet. Anyone can make a statement without having any evidence.
- if all this fails, ask your family doctor to refer you to another endocrinologist for a second opinion.

PROBLEMS TO SOLVE

1. 36 yr old female secondary school teacher. Diagnosed with Addison's disease one year ago. On hydrocortisone 10 mg each morning with breakfast and 10 mg at lunch along with Florinef 0.1 mg each morning.

She is able to work, but feels tired in the morning and when she gets home from school at 4:30 PM she has to have a rest. Her husband gets home at 5:30 and prepares dinner for her and their daughter.

What can we do to improve her situation?

PROBLEMS TO SOLVE

2. A 40 yr old female office worker has Addison's disease and is on hydrocortisone 10 mg each morning, 5 mg at lunch and 5 mg at 4 PM. She is feeling well. She and her family are going to spend 2 weeks in England for a holiday.

What should she do about her medication?

PROBLEMS TO SOLVE

3. 50 yr old male office worker who has Addison's disease has been on cortisone, 25 mg at breakfast, 12.5 mg at lunch and 12.5 mg at 4 PM

He has been on this medication for 10 yrs and has been doing well until the past 6 months when he began to be more fatigued.

What are the things we should consider?

- problems at work?
- changes in his medication?
- other problems?

PROBLEMS TO SOLVE

A fifty year old male who has Addison's disease is on 20 mg of cortisol in the morning and 10mg at noon. He is due to have a colonoscopy next Tuesday.

- What should he do about his cortisol replacement ?
- What should he do if the prep for the colonoscopy causes vomiting so he cannot keep his cortisol down?

OTHER AUTOIMMUNE DISEASES THAT MAY BE ASSOCIATED WITH ADDISON'S DISEASE

- | | |
|-----------------------|-----|
| 1. Thyroid | 50% |
| 2. Diabetes | 10% |
| 4. Ovarian failure | |
| 5. Celiac disease | |
| 6. pernicious anaemia | |
| 7. vitiligo | |

WHAT IS ADRENAL FATIGUE

The adrenal is capable of secreting extremely large amounts of cortisol

Contrary to what you read on the internet, there is no such thing as adrenal fatigue

WHAT IS THE CURRENT STATE OF DHEA

Studies giving DHEA to subjects with Addison's disease have shown mixed results.

- some studies have shown possible beneficial effects with sexual function.
- most studies have shown no beneficial effects
- side effects with doses of 25 to 50 mg daily include acne, hirsutism and increased sweat odour. These occur in 20 to 80% of patients